the ever-widening circle of inclusion

Regional Centers An Historical Perspective



"We as a Nation have long neglected the mentally ill and the mentally retarded. This neglect must end, if our Nation is to live up to its own standards of compassion and dignity and achieve the maximum use of its manpower. This tradition of neglect must be replaced by forceful and far-reaching programs carried out at all levels of government, by private individuals and by state and local agencies in every part of the Union."

# The Era of Institutional Reform

- People who receive services are known as **patients**.
- *Services are institutional and custodial with little, if any, programming.*
- Decision-making about services is based on institutional standards of professional practice.
- Some private services in the community but segregated are provided by the Association(s) for Retarded Children and a few similar parent-driven organizations, without government support.

# Historical Highlights...

1955 In California, five state hospitals (DeWitt, Pacific – later renamed Lanterman - Modesto, Porterville, and Sonoma) house approximately 8,500 people with mental retardation. Over the next 45 years there will be consistent change in the identity of the state institutions serving people with developmental disabilities. At any given time there may be as few as five and as many as nine.

A Special Clinic for the Study of Mental Retardation, funded by the U.S. Children's Bureau, is established at Childrens Hospital Los Angeles.



1959 Operating out of the Special Clinic in Los Angeles is a Traveling Child Development Project, providing diagnosis and counseling in 15 Southern California communities. This project, directed by Dr. Richard Koch, operates on a multidisciplinary model. Art Bolton, who later is involved in developing the model for regional centers, visits the Special Clinic and recognizes its potential as a model for serving people with developmental disabilities throughout the state.

Because publicly-funded services are extremely limited and almost exclusively institutional, across the country families of people with mental retardation create their own support and service systems. In California, parent-run organizations such as the Exceptional Children's Foundation

setting the ctare. 1955, 1965





(Los Angeles), Villa Esperanza (Pasadena), and Aid for Retarded Children (San Francisco) establish private schools, activity centers, sheltered workshops, and residential services.

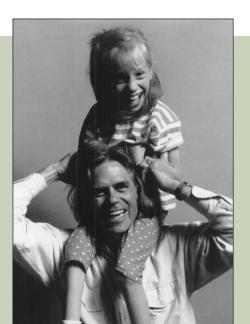
At the Golden Anniversary White House conference on Children and Youth, Dr. Elizabeth Boggs, President of the National Association for Retarded Citizens (NARC); Dr. Gunnar Dybwad, NARC Executive Director; representatives of the American Association on Mental Retardation; as well as a number of university representatives, make many recommendations focusing on the families of persons with mental retardation.

1961 President John F. Kennedy, who himself has a sister with mental retardation, appoints a President's Panel on Mental Retardation. This group is charged with the development of a "National Plan to Combat Mental Retardation." President Kennedy announces his "intention to appoint a panel of outside scientists, doctors, and others to prescribe a program of actions in the field of mental retardation...We, as a nation, have for too long postponed an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected..."

1962 The President's Panel submits its report on October 16, recommending community-based care and a reduction of the number of persons living in large, congregate care facilities.

1963 The White House Conference on Mental Retardation is convened to make recommendations based on the

work of the President's Panel. A legislative package is developed, including amendments to the Social Security Act establishing the Maternal and Child Health Program. A primary goal of this program is to improve prenatal care to high-risk women from low-income families in order to reduce the incidence of children born with disabilities.







Pioneer Profile – Vivian Walter

We're here to speak for justice and humanity for the legal and moral rights of half a million citizens of the State of California who through no fault nor choice of their own are mentally retarded. Vivian Walter

An outspoken and active pioneer in the field of developmental disabilities, Vivian Walter joined San Francisco ARC a year after her son Ned was born with Down syndrome. As part of that group she created a one-woman Hospital Committee and began going to the local state hospitals. It was during those visits that she began to see how desperate conditions truly were - and that realization moved her to act, and set into motion a series of events that would bring about a dramatic change in both the hospitals and the treatment of individuals with mental retardation. Ultimately, these activities would culminate in the Lanterman Act.

Through her friendship with Dr. Gunnar Dybwad, she invited him to California to see the state hospitals first-hand. His reaction added impetus to the growing movement for reform.

She was a member of the board of Golden Gate Regional Center – one of the two pilot centers established in 1966. She was Chair of Mental Hygiene for the California Council for Retarded Children. She also went on to be President of the Board of San Francisco ARC, and vice president of the Southwest Region of the ARC National Board. In addition, she served on the State Board for the Developmentally Disabled under governors Pat Brown and Jerry Brown.





The Mental Retardation Facilities and Community Mental Health Center Construction Act (PL88-164) provides for construction of community-based facilities for people with mental retardation and mental illness.

In California, six state hospitals – Dewitt, Pacific, Fairview, Patton, Porterville, and Sonoma – serve approximately 12,700 people with mental retardation.

Plans are underway to enlarge the state hospital system in California. During an unscheduled visit to one state hospital, a group of people – among them Vivian Walter, then Chair of Mental Hygiene for the California Council for Retarded Children, and a reporter for the *Orange County Register* newspaper – are stunned at the desperate conditions they find. This visit and subsequent publication of the findings prompts a series of hearings and investigations that will lead to dramatic changes in the state hospital system and in the lives of people with developmental disabilities.

1964 Under the impetus of Federal Legislation (PL88-156) and urging from parents through the California Council for Retarded Children (later renamed California Association for Retarded Citizens), the state Legislature appoints "A Study Commission on Mental Retardation."

Retarded of California," is submitted to the governor and legislature by the Subcommittee on Mental Health of the Assembly Interim Committee on Ways and Means. The members of the subcommittee are Assembly Majority Leader Jerome Waldie (chair), Clair Burgener, Frank D. Lanterman, and Nicholas Petris. The principal consultant to the subcommittee is Art Bolton. The report calls for the state to accept responsibility for persons with mental retardation prior to state hospital admission through regional community-based services that would provide "diagnosis, counseling, and continuing services."

Assembly Bill 691 (principal author Jerome Waldie; co-author Frank Lanterman) is enacted and signed by Governor Edmund G. (Pat) Brown. The bill calls for a shift of state responsibility for people with mental retardation from the point where they enter a state hospital to the point where they are diagnosed as mentally retarded. The bill authorizes the establishment of two pilot *regional centers* for persons with mental retardation under contract with the State Department of Public Health. The centers





are designed to call attention to unmet needs of people with mental retardation, facilitate the development of services, maintain records, and provide systematic diagnosis and follow-up. They are also charged with assisting state hospitals in moving their residents to the community.

In his message to the Legislature urging the passage of AB691, Governor Edmund G. Brown states: "Our concern for the mentally retarded is a measure of our adherence to one of the oldest and deepest tenets of western civilization – a reverence for human life and human potential. As we prize the life of the handicapped person and seek to help him develop to the limit of his capacity, we provide for our right to be called civilized. Our major means toward this goal should be education and rehabilitation, not merely protection and custody. Society's as well as the individual's interest can be served here. If the retarded can become more self-sufficient and productive, some may become taxpayers and more active participants in our society. In any event, they will require less expensive services from society than if they were totally dependent."

The Federal Vocational Rehabilitation Act (PL89-333) is amended to mandate that services be provided for people with severe disabilities. It allows more flexible guidelines to permit extended evaluation periods for persons with mental retardation or similar disabilities.

The Social Security Act (PL89-98) is amended to establish the Medicare and Medicaid programs and to provide public funding for care of people with mental retardation and similar disabilities.

More than 13,000 persons with mental retardation reside in overcrowded state hospitals (now called developmental centers) in California, with 3,000 people on waiting lists for admission. People often wait two or three years for admission.

# During This Time in Los Angeles...

1963 A Mental Retardation Joint Agency Project is established to plan for children and adults with mental retardation in Los Angeles County.

1964 The Mental Retardation Services Board is established under a joint powers agreement. The Board recommends the establishment of five regional center areas in Los Angeles County. Eventually seven areas are agreed upon.







"In order to provide fixed points of referral in the community for the mentally retarded and their families; establish ongoing points of contact with the mentally retarded and their families so that they may have a place of entry for services and return as the need may appear; provide a link between the mentally retarded and sources in the community, including state departments, to the end that the mentally retarded and their families may have access to the facilities best suited to them throughout the life of the retarded person; and offer alternatives to state hospital placement, it is the intent of this article that a network of regional diagnostic, counseling, and service centers for mentally retarded persons and their families, easily accessible to every family, be established throughout the state."

# The Era of De-Institutionalization

- People who receive services are known as clients.
- The focus is on moving people out of institutions into the community.
- The service model is primarily medical in nature. Service plans focus on solving "problems" and are prescriptive.
- Services are increasingly community-based, but are still typically provided in segregated settings such as group homes, sheltered workshops and activity centers, and special education schools.

## Historical Highlights...

1966 In California, seven state hospitals – Agnews, Dewitt, Pacific, Fairview, Patton, Porterville, and Sonoma – house approximately 13,200 people with mental retardation.

The President's Committee on Mental Retardation is established on May 11.

In California, SB499 is enacted, establishing Developmental Centers for the Handicapped, segregated public schools for handicapped children.

The two pilot regional centers are established. The Department of Health

negotiates contracts with two private agencies: Childrens Hospital Los Angeles (to serve Los Angeles County) and San Francisco Aid for Retarded Children (to serve Alameda, Contra Costa, Marin, San Francisco, and San Mateo counties). These two organizations are charged with contacting people on waiting lists for admission to state hospitals, providing diagnostic assessments, and making recommendations for community-based care. Very limited funds are available to

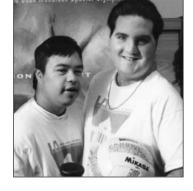


the centers to purchase services. The initial budget for the two pilot regional centers is \$966,386. They will serve a total of 559 clients at an average cost of \$1,728 per person.

1967 Neils Bank-Mikkelson, internationally recognized expert in the field of mental retardation and Director of the Danish National Services for the Mentally Retarded, visits Sonoma State Hospital. He is stunned







by the shocking conditions he observes. He states publicly that in Denmark cattle are treated better than people are treated in California's state hospitals. His statements about what he sees cause a public outcry in California and result in Assemblyman Lanterman's call for an investigation into the system.

1968 By June of this year the two pilot regional centers are serving 770 clients and their families.

The number of people with mental retardation living in state institutions peaks at approximately 13,400.

1969 The California State Employees' Association (CSEA) sues to halt the further development of regional centers, arguing that the state constitution requires these services to be provided by state employees. A court decision by Judge B. Abbott Goldberg determines that: "The fact that a particular occupational skill can be provided by civil service does not mean that the function of a program can be achieved through civil service. To use a homely metaphor, the fact that one can buy ingredients does not prove he can bake a pie."

"A Proposal to Reorganize California's Fragmented System of Services to the Mentally Retarded" is reported to the State Assembly. Dennis Amundson, an aide to Assemblyman Frank Lanterman, is the principal drafter. The report concludes that the pilot regional centers are successful and the model should be expanded statewide.

Assemblyman Frank Lanterman introduces AB225 that extends the regional center network of services throughout California and establishes area boards for planning and monitoring of services. The system will be composed of 21 regional centers, one for every 1 million residents of the state.

AB225 is enacted and signed by Governor Ronald Reagan on September 4, 1969. Governor Reagan states that "California is currently preparing to implement the Lanterman Mental Retardation Services Act. That progressive legislation provides us with a dynamic framework on which we shall build a comprehensive system to assure that the mentally retarded develop to the fullest extent to which they are capable. The purpose of this legislation is to meet the needs of each retarded person, regardless





Pioneer Profile – Frank D. Lanterman

Frank D. Lanterman represented the La Cañada area of Los Angeles County in the State Assembly for 28 years, starting in 1950. He served as chairman of the Sub-Committee on Mental Health and Developmental Disabilities for many years. During that time, he did more than any other legislator to improve the lives of persons with developmental disabilities and their families. Through a number of legislative efforts, he played a key role in increasing the care and opportunities available for persons with disabilities and ensured that care would be provided closer to their homes and families.

He retired from the Legislature in 1980 and died in 1981. Others have aspired to wear his mantle, but none have achieved his stature.

The Memorial Resolution passed in his honor reads, in part:

"Whereas, he leaves behind a legacy of leadership, a history of lessons for present and future politicians; and he fashioned permanent progress for the sick in body and mind, following in his father's footsteps; Frank Lanterman was a healer on a grand scale; now, therefore, be it resolved by the Joint Rules Committee of the Senate and the Assembly...that the Legislature will pursue and preserve Frank Lanterman's vision of his beloved state and emulate his tenacity for justice for all the people of California."



of age or degree of handicap, and at each stage of his life's development." The act calls for the state to contract with local, community-based non-profit corporations.

The U.S. Supreme Court hands down a decision in the matter of *Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania* affirming the right to education at public expense and due process for children with disabilities.

1970 The Urban Mass Transportation Act (PL91-453) is amended to require local governments to ensure that mass transportation facilities and services are accessible to people who are elderly or handicapped.

The Developmental Disabilities Services and Facilities Construction Act (PL91-517) is amended. This act integrates previous legislation addressing developmental disabilities into a comprehensive statute that also requires every state to establish a governor's council on developmental disabilities.

1971 DeWitt State Hospital becomes the first California hospital serving people with mental retardation to close its doors.

1972 The decision in *Wyatt v. Stickney*, an Alabama class action suit filed in federal district court, sets forth the constitutional right to developmental and rehabilitation treatment in the least restrictive environment for persons committed to a state institution without a criminal trial.

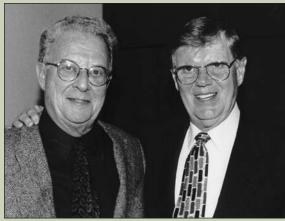
Social Security Act Amendment PL92-603 establishes Supplemental Security Income (SSI) to standardize assistance programs to people in need, including those with developmental disabilities.

1973 AB846, authored by Assemblyman Frank Lanterman, extends the regional center mandate to other developmental disabilities, including cerebral palsy, epilepsy, autism, and other neurological handicapping conditions closely related to mental retardation.

The Rehabilitation Act of 1973 (PL93-112, Section 504) authorizes over \$1 billion for training and placement of persons with mental and physical handicaps into employment. Section 504 of this act prohibits discrimination based on disability and provides the legal basis for subsequent anti-discrimination lawsuits.

1974 President Nixon signs Executive Order 11776 reaffirming a national goal of returning one-third of the 200,000 persons with mental retardation residing in institutions to community settings.





The U.S. Department of Justice files a class action suit (*United States v. Solomon*) on behalf of people with mental retardation living in institutions. The decision affirms their right to treatment.

1975 Investigative journalist Geraldo Rivera exposes conditions endured by people with mental retardation living at the Willowbrook State School in New York. Because of underfunding of this institution, residents are living in squalid conditions, largely unsupervised. The exposé results in a lawsuit, New York Association for Retarded Citizens v. Carey. In its decision in this case, the U.S. District Court in Brooklyn reaffirms the constitutional right to treatment in the least restrictive setting and the "most normal living conditions possible."

Congress passes the Education for All Handicapped Act (PL94-142) mandating a free, appropriate public education in the least restrictive environment for all children, regardless of the severity of the child's disability. It also mandates Individual Educational Plans (IEPs) with special education and related services designed to meet the unique needs of each child.

The Developmental Disabilities Assistance and Bill of Rights Act (PL94-103) mandates a bill of rights for persons with developmental disabilities and requires each state to establish a protection and advocacy system.

The 1975-76 budget for all regional centers is \$47,980,527. They serve 33,833 clients at an average cost of \$1,418 per person.

Approximately 10,200 persons with developmental disabilities reside in state hospitals.

## During This Time in Los Angeles...

1975 The annual budget for Childrens Hospital Los Angeles Regional Center is \$2,641,397. The Center serves 1,560 clients at an average cost of \$1,693 per client.





# "Surely, in a mature society, all persons, regardless of the level of their intellectual ability, should and must be

fully accepted."

Dr. Richard Koch

# The Era of the Developmental Model

- The focus in service delivery is on planning for the individual.
- The service model is based on the principle of incremental development with services organized on a continuum in the "least restrictive environment" in order to achieve "normalization."
- Services are organized mainly as structured programs that serve groups of people who "fit" predetermined entrance and exit criteria.

# Historical Highlights...

1976 In O'Brien v. Superior Court, a California court finds that individuals with mental retardation who have been committed to a state institution for being a danger to self or others have the right to a jury trial.

In The Matter of Andre Bisagna, the California Supreme Court orders that, if a person is judicially committed to a state institution for the mentally retarded because of danger to self or others, that commitment order shall expire after one year. The Court further orders that regional centers be notified of all persons who are judicially committed to a state institution. Each regional center shall conduct an annual assessment to determine each person's ability to live in the community.

> The Lanterman Developmental Disabilities Services Act is amended after extensive legislative hearings. The act affirms the right to treatment and habilitation services for persons with developmental disabilities. It changes the last category of eligibility for services to read "handicapping conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, but shall not include other handicapping conditions that are solely physical in nature." It also establishes an individualized planning process to replace the traditional problem-oriented record.

The Regional Center of the East Bay is the last of the 21 regional centers to be established.

Nine state hospitals – Agnews, Camarillo, Pacific, Fairview, Napa, Patton,

Porterville, Sonoma, and Stockton – serve approximately 10,100 people with developmental disabilities.







1977 In *Pennsylvania Association for Retarded Citizens v. Pennhurst School and Hospital*, a federal court rules that keeping persons with mental retardation in institutions isolated from society is a violation of the 14th Amendment to the U.S. Constitution.

1978 Proposition 13 is approved by the voters of California. Its effect is to limit the ability of local governments to generate property tax revenue, thereby shifting greater responsibility and control for services to the state. Assemblyman Lanterman strongly opposes Proposition 13 because he believes it will give too much power to the state while weakening local control, which he calls "home rule." At the same time, the climate for funding of state financed health and welfare programs changes as revenue projections and the state's economy decline.

State hospitals serving people with developmental disabilities are renamed as state developmental centers.

Under Governor Jerry Brown, the Department of Developmental Services (DDS) is established as an independent agency rather than a division of the Department of Health.

The Lanterman Act is amended to create a Program Development Fund to support additional community-based resources for people with developmental disabilities. The fund is to be supported by parental fees collected from parents whose minor children are in out-of-home placement.

1979 The 21 regional centers form the Association of Regional Center Agencies (ARCA), a non-profit state association comprised of regional center board volunteers and executive directors. The purpose of this organization is to promote statewide regional center issue resolution, advocacy, and coordination.

1980 The state eliminates its Continuing Care Services Branch and transfers to regional centers the responsibility for people with developmental disabilities living in board and care and other community care facilities. With this change, regional centers assume responsibility for all aspects of out-of-home living for people with developmental disabilities.

Assemblyman Frank Lanterman retires from the legislature after 28 years. He dies one year later. Other members of the legislature aspire to wear his mantle but none achieves his stature.

A provision of the Social Security Act Amendments (PL96-265) creates a three-year demonstration project that allows SSI recipients with developmental disabilities to continue receiving these benefits while engaged in paid employment.







Pioneer Profile – Jerome Waldie

For the parent of a retarded child, there were only two options. One you kept the child home, or two you would institutionalize the child.

There was nothing in between.

Jerome Waldie

Jerome R. Waldie served California as an Assemblyman from 1959 through 1966. For six of those years he was the majority leader. And in 1965, along with Assemblymen Greene, Lanterman, Alquist, Burgener, Petris and Warren, he introduced AB691, the landmark bill establishing regional centers.

He was subsequently elected to Congress in 1966 where he served until 1975. During that time he was a member of the House Judiciary Impeachment Committee. He later worked for the Carter Administration as Executive Director of the White House Conference on Aging, and as Chair of the Federal Mine, Safety, and Health Review Commission.

He was also a member of the California Agricultural Labor Relations Board and President of the National Senior Citizens Law Center. He is currently active as a member of the Tahoe Regional Planning Agency.





The California Penal Code is amended to require regional centers to provide assessment and recommendations to the court on developmentally disabled defendants in criminal actions.

1981 In the case of *In Re Hop*, the California Supreme Court rules that any adult with developmental disabilities who has been placed in a state hospital is entitled to a judicial review to determine whether he or she should remain institutionalized. The case is later extended to include judicial review prior to admission.

Section 2176 of the Omnibus Reconciliation Act (PL97-35), "Home and Community-Based Waiver" (referred to as "Medicaid Waiver"), allows states to finance a wide array of community services through Medicaid by asking the government to waive the requirement that recipients of the benefits live in institutions. The program funds a number of services that people with disabilities need to live outside of a health facility, such as state developmental center, nursing home, or intermediate care facility. It is intended to facilitate movement to the community from these institutions and to divert admissions.

The California Probate Code is amended, establishing a limited conservatorship for adults with developmental disabilities. This conservatorship "may be utilized only as necessary to promote and protect the well-being of the individual [and] shall be designed to encourage the development of maximum self-reliance and independence of the individual."

Pacific Developmental Center is renamed Lanterman Developmental Center, in honor of Frank D. Lanterman. Some regard this as ironic, since Mr. Lanterman worked throughout his career to ensure community-based alternatives to state institutions.

1982 A Social Security Act Amendment (PL97-248, "Katie Beckett") permits states to use Medicaid funds for children with disabilities who are 18 years of age or younger, who are living at home, and who would be eligible for SSI if they were residing in institutions. The impetus for this change comes in the form of a personal appeal to President Ronald Reagan from Katie Beckett's mother. Because of the Beckett family's income, Katie does not qualify for SSI while living at home, although she would qualify if she lived in an institution. At the same time, her family cannot afford to keep her at home due to the medical and associated expenses associated with her disability.

Patton State Hospital closes its programs for people with developmental disabilities.

1983 California is confronted with a \$1 billion budget deficit. AB40X, authored by Assemblyman Burt Margolin, provides emergency regional center funding and gives DDS emergency authority to directly control regional center expenditures. Service reductions are authorized at ten regional centers.

California is approved for participation in the federal Medicaid Waiver Program.

Education Amendments (PL98-199) establish and fund services to facilitate the transition of students with disabilities from school to the community or work settings.

1984 Regional centers continue to feel the effects of significant reductions in funds for staff and limitations on purchase of service funds. Quality assurance standards, provider rates, prevention, development of service standards, Medicaid Waiver, and installation of a computerized uniform fiscal system are major system issues.

Carl Perkins Vocational Technical Education Act (PL96-524) mandates development of quality vocational education programs and expansion of existing programs with a 10% "set-aside" to support programs for individuals with disabilities.

In response to the "Baby Doe" decision, *United States v. University Hospital*, the federal government mandates reporting of medical neglect if treatment is withheld from infants with disabilities. The decision and the government's action marked an official end to discrimination in medical treatment against infants with disabilities.

1985 Serious state budget deficits cause DDS to reduce funding for regional centers, and, in turn, cause some regional centers to implement costsaving strategies such as waiting lists and categorical cuts in services. In the Association for Retarded Citizens v. California Department of Developmental Services et al., the California Supreme Court rules that the Lanterman Act "defines a basic right and a corresponding basic obligation...[T]he right which it grants to the developmentally disabled person is to be provided with services that enable him to live a more independent and productive life in the community; the obligation which it imposes on the state is to provide such services." These services are to be determined through the individual program planning process and provided as an entitlement. The decision also states that the regional centers, not DDS, have wide discretion in determining how to implement the IPP, but no discretion at all in determining whether to implement it. The Court prohibits the use of cost-saving strategies such as those used by the defendant regional centers. At the same time, the court rules that this does not give regional centers the authority to overspend their budgets. If regional center budgets are not sufficient, DDS must inform the state legislature which must, in turn, either increase funding or statutorily change the entitlement.

The annual budget for all regional centers is \$317,803,208. They serve 78,312 people at an average cost of \$4,058 per person.

In California, eight state hospitals house approximately 7,100 residents with developmental disabilities.

## During This Time in Los Angeles...

- 1976 By this year, six additional regional centers have been created in Los Angeles County. Childrens Hospital Los Angeles Regional Center, which originally covered the entire county, retains responsibility for the north-central area of Los Angeles, Burbank, Glendale, Pasadena, and La Cañada. It celebrates its first decade of service.
- 1978 Childrens Hospital Los Angeles Regional Center moves its offices from the main hospital campus to the Pico-Union district of Los Angeles, and closes its branch offices.
- 1979 The regional center legally separates from Childrens Hospital Los Angeles under a free-standing non-profit corporation, the Los Angeles County Developmental Services Foundation, Inc. Mrs. Asenath Young, one of the incorporators, is its first President. The Center is named after Assemblyman Frank D. Lanterman.
- 1985 Lanterman Regional Center's annual budget is \$13,483,971. The Center serves 3,321 clients at an average cost per client of \$4,060.



# "Let the shameful wall of exclusion finally come tumbling down."

President George Bush on signing the Americans with Disabilities Act, 1990

# Commitment to inclusion. Des Service. 1986-1995

# The Era of Community Inclusion

- The person receiving services is known as a **consumer**.
- Services and supports replace programs.
- The individual and his or her family direct the planning process; decisions are made in a collaborative way, involving the consumer's circle of support.
- Individuals and their families are given increasing access to information and are encouraged to use it.

# Historical Highlights...

1986 Amendments (PL99-457) are attached to the Education for All Handicapped Act, mandating pre-school programs for three- to five-year-olds and planning for early intervention programs for infants and toddlers with disabilities or who are at risk, and their families.

In California, eight state hospitals - Agnews, Camarillo, Lanterman, Fairview, Napa, Porterville, Sonoma, and Stockton – serve approximately 6,900 people with developmental disabilities.

1988 California is approved for participation in the federal Targeted Case Management Program, providing the state with federal funds to defray some of the costs of case management. It is a milestone in DDS's efforts to shift funding responsibility for services from the state general fund to the federal Medicaid program.

The Technology Related Assistance for Individuals with Disabilities Act (PL100-407) provides financial assistance to persons with disabilities to purchase assistive devices.

Fair housing amendments to the Civil Rights Act of 1968 extend the principle of equal housing opportunity to persons with disabilities.

1989 A Senate Resolution (SR9), authored by Senator Dan McCorquodale, results in gather extensive testimony concerning the Lanterman Developmental Disabilities





The Omnibus Budget Reconciliation Act (PL101-239) provides a work incentive that allows SSDI recipients with disabilities who return to work to purchase Medicare coverage after they have exhausted the trial work period and the extended period of eligibility. The act requires the Medicaid program to pay the Medicare premium for SSDI recipients earning less than 200% of poverty level.

1990 The Americans with Disabilities Act (PL101-336) establishes basic civil rights of persons with disabilities, barring discrimination in employment, and requiring accessibility in transportation, public accommodations, and all government facilities, services, and communications. The ADA also requires telecommunications devices for the deaf to be provided by companies offering telephone service to the general public.

The Individuals with Disabilities Education Act (PL101-476) extends eligibility categories and required services under the Education for All Handicapped Act.

1991 Dennis Amundson, once an aide to Assemblyman Frank Lanterman, is named Director of DDS.

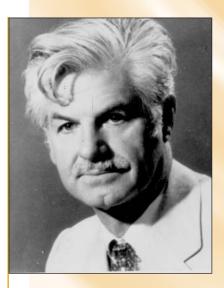
Owing to a nationwide recession, the state budget deficit exceeds \$1.5 billion. The regional centers are required to submit "expenditure" plans outlining how they will absorb significant budget reductions.

California is one of eight states chosen to receive a federal grant under the Community Supported Living Arrangements (CSLA) program. Seven regional centers are chosen to administer the grant. Under the CSLA program, consumers own, lease, or rent homes or apartments and receive the support services necessary for them to live independently in these settings. This is the first adequately funded, formal initiative aimed at coordinating all of the support needs of people with developmental disabilities living on their own in the community.

1992 SB1383 (McCorquodale) makes significant changes to the Lanterman Act, updating the philosophy and expanding the range of services and supports available to consumers and families. The value statements embrace the concept of "empowerment," giving consumers and families more choice and more authority to make decisions about their own lives, but they also state explicitly that the changes do not constitute an expansion of the entitlement.

The budget situation in California worsens, with a deficit of almost \$11 billion. In response to the continuing financial crisis in the state, SB485 is enacted to ensure access to services within the limits imposed by the





Pioneer Profile – Dr. Richard Koch

I realized very quickly after we got into this work that it was all well and good for us to spend all this time and energy, but if the family couldn't carry out what we intended for them then it was wasted.

Dr. Richard Koch

An internationally recognized expert on PKU (a metabolic disorder which causes mental retardation), Dr. Richard Koch stands on more than 40 years of continuous commitment to individuals with developmental disabilities. He was an early advocate in the fight to keep people out of institutions, provide support for families to keep children at home, and ensure community living options for adults.

In the 1950s, he served as
Director of the Clinic for the
Study of Mental Retardation, and
then as Director of the Traveling
Child Development Project which
provided assessment services and
advice to parents with children
with developmental disabilities
in 15 Southern California
communities.

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budget. This act states in part: "The Legislature finds that the state faces an unprecedented fiscal crisis...In order to ensure that services to eligible consumers are available throughout the contract period, regional centers shall administer their contracts within the level of funding available within the annual Budget Act...Regional centers shall implement innovative, costeffective methods of service delivery..."

DDS establishes an Office of Consumer Affairs. Michael Long, a person with a developmental disability, is appointed to direct the office. Mr. Long is the first person with a developmental disability to be appointed by any governor in the United States to such a high level post.

DDS establishes Regional Resource Development Projects joining developmental centers and regional centers with which they share consumers in an effort to promote the movement of developmental center residents into the community. Eventually, all seven developmental centers become involved in these projects requiring coordinated resource development and service planning.

1993 Thirteen state developmental center residents and their families file a class action lawsuit against DDS and four regional centers, with the goal of ensuring that persons with developmental disabilities have access to quality, stable, individually tailored, and integrated community living arrangements of choice (*William Coffelt, et al. v. Department Of Developmental Services, et al.*). An out-of-court settlement results in the adoption of the Community Living Options Initiative calling for movement of 2,000 persons from developmental centers into the community over five years and the prevention of future inappropriate admissions. The \$334,023,000 needed to fund the initiative is to come from an expansion of the Medicaid Waiver Program.

California implements the Federal Part H Early Intervention Program through SB1085, the California Early Intervention Services Act. This legislation called "California Early Start," requires statewide services for eligible infants and toddlers from birth to 36 months. It also authorizes the development of Family Resource Centers in the community to provide information and referral to families of children receiving early intervention services.

1994 DDS enters into an agreement with the Department of Housing for a \$4 million bond issue targeted at affordable housing for people with developmental disabilities.

1995 In California, seven state developmental centers serve approximately 5,100 persons. The decline in the developmental center population, from a high of almost 13,500 in 1966, results in several thousand empty beds across the seven existing campuses. Because of the inefficiencies and the cost of operating seven aging facilities, a plan is put in place to close some of these institutions. Stockton Developmental Center – the oldest such institution west of the Mississippi, first opened in 1851 – is set for closure.

The annual budget for regional centers is \$941,515,000. The 21 centers serve 129,230 consumers at an average cost of \$7,285 per person.

Nearly 60% of regional center support now comes from federal program funds.

## During This Time in Los Angeles...

- 1986 Lanterman Regional Center celebrates its second decade of service to an increasingly ethnically diverse population. The center moves from Pico-Union to Wilshire Center.
- 1991 Lanterman Regional Center prepares its first expenditure plan setting out how it intends to save almost \$1.6 million. In this first year, the Center appeals to the community for help and the response is extraordinary. Restructuring efforts, including a voucher system for transportation and respite, wherein families are given funds that allow them to purchase their own services, result in savings of almost \$2 million.
- 1992 Because of the worsening budget situation in California, Lanterman Regional Center experiences cuts to direct services of \$760,000. Over two years, the Center loses 25% of its staff. The Board decides that the fiscal crisis in California is not short term and that the center needs to begin moving toward a different model of service delivery. It adopts a plan to decentralize service coordination into four geographic teams.
- 1993 Recognizing the critical need for the community to have access to nformation and resources, the center establishes the Koch Young Family Resource Center, honoring parent-professional partnerships and the two individuals who exemplify them, Dr. Richard Koch and Mrs. Asenath Young. The decision is made to provide information and referral services to all families, not only those receiving early intervention services, as well as to professionals who serve people with developmental disabilities.
- 1994 The Board adopts a framework for establishing a new paradigm for the Center. This is reflected in the document "Transforming the Regional Center for the 90s and Beyond: A Framework for Action."

Steps in the Center's transformation include: institution of regional community advisory councils; establishment of a volunteer program with over 180 volunteers contributing more than 5,000 hours of service; support for 23 self-directed support groups in the community; and a leadership development training program, exemplified by the first Lanterman Summer Leadership Institute.

The Board establishes a Strategic Planning Committee to develop a strategic plan for the five-year period, 1996-2000. While the Center is required by state law to develop a performance plan, the Board decides to integrate the performance planning process within the more comprehensive strategic planning activity.

1995 The 1995-96 budget for Lanterman Regional Center is \$32,390,557. The Center serves 4,595 consumers at an average cost of \$7,049 per person.



(Pioneer Profile – Dr. Richard Koch continued)

In the early 60s, he was President of the California Council for Retarded Children (which became the Association for Retarded Citizens, California) and of the American Association on Mental Retardation. During that time he advocated for the establishment of the regional center system. In 1966, he became the first Director of the Childrens Hospital of Los Angeles Regional Center.

From 1975 to 1977, he served as Deputy Director of the State Department of Health. For a number of years, Dr. Koch has also provided medical consultation to the Los Angles County Jail in assessing individuals who are suspected of having a developmental disability.

Today, he continues to see long-term patients and families in the Department of Genetics at Childrens Hospital of Los Angeles. He also serves as a member of the Lanterman Regional Center Health Care Task Force.

Past Board Presidents joined in celebrating the opening of the Koch-Young Family Resource Center. Pictured are (l-r) Al Marsella, Dr. Koch, Katie Nack, Asenath Young, Carol Larson, Sharman Jamison, James McDermott, and Philip Grant.

"Though progress has been made in the last decade, too many barriers remain. Too many Americans with disabilities remain trapped in bureaucracies of dependence and are denied the tools and access necessary for success...People with disabilities want to be employed, educated, participating, tax-paying citizens living in the community and contributing to the economic and social fabric of American life. And, in today's global new economy, America must be able to draw on the talents and creativity of all its citizens."

> President George W. Bush Announcing his "New Freedom Initiative" February 1, 2001

# The Era of Empowerment

- The person receiving services is a fully included member of the community.
- Services are integrated and flexible and provided where people need them in natural environments.
- *Individuals and families direct the planning process, guided by* the individual's desired outcomes.
- *Individuals and families are given the information, training,* and support necessary for them to exercise choice, and make their own decisions.

## Historical Highlights...

1996 Stockton Developmental Center becomes the second such institution in California to close.

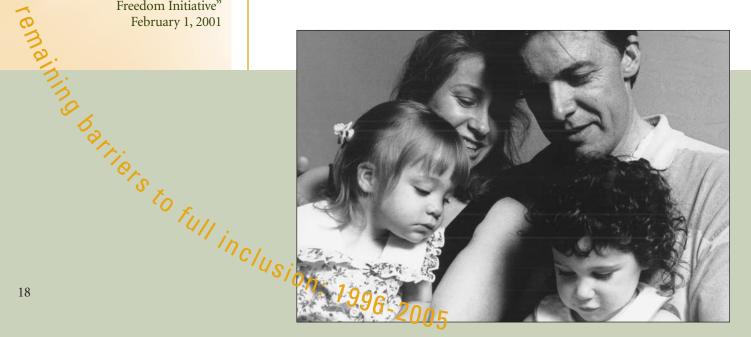
Napa State Hospital again starts serving people with developmental disabilities, after an eight-year hiatus.

Seven state hospitals – Agnews, Camarillo, Lanterman, Fairview, Napa, Porterville, and Sonoma – serve a total of 4,500 people with developmental disabilities.

1997 Camarillo Developmental Center becomes the third such institution in California to close.

The net reduction of 2,000 persons from the state developmental centers, as specified in the Coffelt Settlement of 1993, is achieved, one and onehalf years ahead of schedule.

David Strauss and several colleagues release the "Strauss Report" that uses statistical analysis of a state database to attempt to establish that there is a higher rate of mortality among consumers living in the community than among consumers residing in developmental centers. While its methodology is questioned and its results not replicated, the study generates wide press coverage throughout California. The San Francisco Chronicle, in a series of articles, presents a biased view of communitybased services and a system in crisis because of under-funding and



poorly qualified direct care staff, particularly in residential facilities. Regional centers are heavily criticized for not ensuring the quality of services provided in the community.

Using the Strauss Report as evidence, unions representing state employees and the California Association of State Hospital Parent Councils for the Retarded argue against additional closures of state developmental centers. As a result, Agnews State Developmental Center, scheduled to close, is removed from the closure list. Dennis Amundson, the Director of DDS, resigns amid controversy.

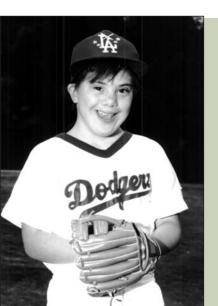
Prompted by the Strauss Report and the accompanying controversy, Senator Mike Thompson conducts statewide hearings to solicit recommendations for improving community-based supports and services. Provisions in two subsequent bills, SB1039 (Thompson) and SB391 (Solis) are intended to ensure appropriate monitoring of people who move from state developmental centers into the community. Provisions include reinstatement of quarterly monitoring of consumers living in residential care facilities; transfer of formal assessment of quality of life of people living in the community from regional centers to area boards; and movement of the position of Client Rights Advocate from regional centers to Protection and Advocacy, Inc. (PAI).

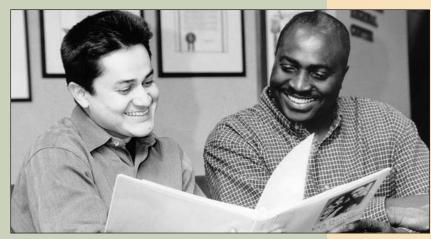
PAI establishes the Office of Clients' Rights Advocacy, a semi-autonomous entity with an independent advisory council, to assume the advocacy function for people with developmental disabilities. Regional centers, however, retain the responsibility for advocacy as spelled out in the Lanterman Act.

1998 In response to the Strauss Report and subsequent publicity, the Health Care Financing Administration (HCFA) audits California's compliance with its Home and Community-Based Waiver Program, and issues a report critical of the state's community-based system of care for people with developmental disabilities. HCFA demands a number of reforms as a condition of California's continued participation in the waiver program, a program that would bring almost \$450 million to the state.

Throughout the state, local stakeholder groups review the current developmental services system and make recommendations for change. Resulting bills, SB1038 (Thompson) and AB2780 (Gallegos), address issues concerning structural and rate reforms for community-based services. These pieces of legislation are aimed at developing equitable and cost-effective rates based on performance and consumer outcomes for residential services,









supported living, day programs, and respite. A statewide stakeholder advisory group guides this process of *system reform*. Three principal work groups are organized to develop personnel standards, performance accountability and quality assurance, and rates and budget. Significant changes to the Lanterman Act follow.

One provision of SB1038 calls for the implementation of Self-Determination Pilot Projects at three (later four) regional centers. Under these projects, consumers and families are allotted an amount of money based on what the regional center spent on them in prior years. They are permitted to make their own decisions about how this money should be spent in the interest of the consumer. They also are asked to assume some responsibility for negotiating service arrangements and paying service providers.

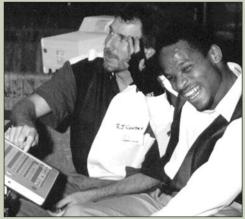
Citygate Associates conducts an independent evaluation of community placement practices. It is primarily intended to allow judgments about the success of the program aimed at moving developmental center residents into the community as required by the Coffelt Settlement. Among the findings are that people moving into the community have a better quality of life than people remaining in developmental centers, and the mortality rate for people in the community is lower than that for people remaining in developmental centers.

A study of the buildings and infrastructure of the five developmental centers by Vanir Engineering Corporation, yields the conclusion that repair or replacement of the facilities would cost between \$800 million and \$1.5 billion.

Lanterman, Harbor, and Golden Gate Regional Centers partner with the University of Southern California School of Cinema-Television and Union Bank of California to produce "We're Here to Speak For Justice." This hour-long documentary film tells the story of the development of the regional center system in California. The film, produced and directed by award-winning filmmaker, Theodore Braun, is shown on public television stations KCET in Los Angeles and KQED in San Francisco. The film and its companion book of the same name introduce the pioneering family members, legislators, and other professionals of California whose courage, commitment, and vision led to the development of the community-based system of services for people with developmental disabilities.

1999 In California, an increase of \$207 million (17.7%) is provided for community services in the 1998-99 Budget Act. The budget increase includes funding for specific purposes – for example, to ensure that regional centers average a 1:62 service coordinator to client ratio, thereby enhancing





regional centers' ability to protect the health and safety of consumers. Regional centers remain significantly under-funded in all other areas of staffing and operations, however.

A report by the Bureau of State Audits required by the 1997-98 Budget Act concludes that the budget and allocation process used by DDS to fund regional centers does not ensure that clients throughout the state have equal access to needed services. The audit finds that DDS is not ensuring that regional centers are properly staffed and that their clients have equal access to case managers. The report concludes that the success of the system has been undermined by insufficient state funding and more than \$106 million in budget cuts over a four-year period.

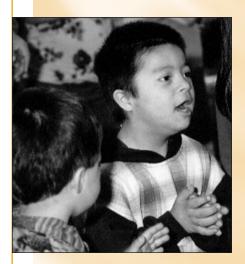
The state recognizes that the budget methodology that has been used for years to fund regional center staff and operations is outmoded. Citygate Associates is commissioned to conduct a legislatively mandated study of the budgeting methodology for funding regional center staff and operating expenses which will enable regional centers to meet their state and federal mandates and be consistent with good business and professional practice.

In *Olmstead v. L.C.*, the U.S. Supreme Court holds that the Americans with Disabilities Act prohibits "unjustified isolation" in institutions. Institutional placement is "unjustified" when the state's treating professionals have determined that community placement is appropriate, when the individual does not oppose community placement, and when the placement can be reasonably accommodated considering the state's resources and the needs of others with disabilities. In this decision, the Court also supported the notion that a state can be required to fund community placements by moving resources from institutions to the community.

A report released by DDS shows that there are no significant differences between the type and severity of disabilities of people living in developmental centers and those living in the community.

2000 In a time of unprecedented state and federal budget surplus, the regional center system is in crisis. While the late 1990s saw an increase in regional center funding for specific purposes (e.g., decreasing caseload ratio), the cuts imposed on regional centers in the early 1990s were never restored. Regional centers are overwhelmed with unfunded mandates and rising expectations of consumers and their families. A November 2000 survey of regional centers finds that virtually all centers cite their lack of ability to hire and retain an adequate number of service coordinators and other key positions as their chief operational problem. In addition, the purchase









of services budget is a closed-ended allocation intended to fund an openended entitlement that expands with the increasing expectations of consumers and families.

Anticipating the apparent closure of state developmental centers, the FY2001 Budget Act mandates DDS to prepare a report by March 1, 2001 on "a range of options to meet the future need of individuals currently served, or who will need services similar to those provided, in state developmental centers." DDS is to examine various options in conjunction with a work group of stakeholders, and evaluate options for "appropriateness in meeting consumers' needs, compliance with federal and state laws, and efficient use of state and federal funds."

DDS creates an advisory committee to help determine the future of state developmental centers and consumers who reside in them. This group recommends five principles, including: 1) no capital outlays to rebuild developmental centers; 2) homes in the community no larger than four residents; 3) put developmental center resources to work in the community; 4) leverage developmental center land to create new resources; and 5) conduct individualized personal assessments and resource development for people moving to the community. The committee's principles and recommendations are used as the basis for conducting surveys and focus groups of stakeholders.

DDS commissions Judith Poindexter to survey stakeholder groups regarding their opinions relative to options for developmental centers developed by the advisory committee. The data gathering activities result in strong and heated reactions from stakeholders while providing a clear consensus: people want a unified service system in the community.

*In The Case of Richard S.*, a federal court in California finds that third parties – parents, guardians, or conservators – may not waive a developmental center resident's right to move to the community. A permanent injunction is issued against the DDS policy that allows family members or conservators to "veto" community placement from a developmental center, when such a move is deemed to be appropriate for the consumer.

DDS leases Sierra Vista, the first of two 50-60 bed institutions to house people with developmental disabilities. These facilities are intended to serve the growing population of people with behavioral and forensic needs in state institutions.

PL106-448 allows the U.S. attorney general to waive the requirement that naturalization applicants take an oath of allegiance if the applicant is unable to understand or to communicate an understanding of the law's meaning because of a physical or developmental disability, or a mental impairment

2001 Seven people with developmental disabilities, their families, and six organizations file suit in federal court against the State of California on behalf of people living in developmental centers and others who are denied access to high quality, community-based services (*Sanchez v. Johnson*). They charge that chronic under-funding of community services and supports denies citizens with developmental disabilities their civil right to appropriate treatment in the least restrictive environment.

The Association of Regional Center Agencies publishes a strategic document entitled, "Planning for a Unified Developmental Disabilities Services System: A report to Californians with developmental disabilities and their families." The report endorses the development of a unified, coordinated community service system focused on outcomes.

Assemblywoman Dion Aroner puts forth a concept paper for legislation aimed at unifying the developmental disabilities system, rather than maintaining the current state/community division. Her legislation would unify the budget and resources of developmental services, apply the same personal outcome and quality standards to all programs, develop personnel standards for all workers in the system, and establish a uniform rate system. Art Bolton, who was instrumental in the original design of regional centers, comes out of retirement to assist Assemblywoman Aroner in the development of this legislation.

Welfare and Institutions Code 4791 is scheduled to "sunset." This statute resulted from SB485, passed in 1992, requiring regional centers to administer their contracts within the reduced level of funding available in the budget of that year. Stakeholders anticipate considerable debate as to whether or not this statute should be allowed to sunset.

President George W. Bush announces his *New Freedom Initiative*, a series of proposals intended to help "ensure that all Americans with disabilities have the tools to use their skills, and make more of their own choices. [This] initiative will increase investment in and access to assistive technologies and a quality education, and help integrate Americans with disabilities into the work force and into community life."

President Bush also issues an Executive Order calling for swift implementation of the *Olmstead* decision (1999).

The annual budget for all regional centers is \$1,877,800,000. They serve 162,970 clients at an average cost of \$11,522 per person.

Approximately 3,800 persons reside within six state developmental centers.

# During This Time in Los Angeles...

1996 Lanterman Regional Center celebrates three decades of service and sponsors the *Lanterman Leadership Forum: A Community in Action*. Three hundred community leaders, representing consumers, parents, service providers, community organizations, and staff attend. Themes are derived from the center's strategic plan: community ownership, partnership, continuous learning, and continuous improvement.

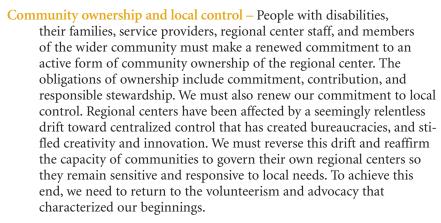
Following 18 months of planning, the Center's first strategic plan is launched. The plan covers eight major areas with 39 strategic goals and more than 100 objectives. By the end of 1996, almost all of the first year objectives are achieved – a remarkable accomplishment.

- 1998 To accommodate its substantial growth, Lanterman Regional Center moves several blocks east on Wilshire Boulevard to its current home.
- 2001 The annual budget for Lanterman Regional Center is \$55,873,000. The Center serves approximately 5,500 clients at an average cost of \$10,160 per client.

Lanterman Regional Center embarks on its second 5-year performance plan. The center also holds its second *Lanterman Leadership Forum...*Our Customer Values in Action, to celebrate 35 years of service to the community.



# Leadership Challenges For This Era



Social acceptance and full inclusion of people with developmental disabilities — We have made substantial progress toward integration of children and adults with developmental disabilities in the areas of education, employment, and community life in America. Legislative initiatives and judicial decisions, as well as the recent "New Freedom Initiative" of President George W. Bush, promise an ever-widening circle of inclusion. At the same time, social acceptance and full inclusion remain ideals. We must continue to work diligently to bring down the barriers faced every day by people with disabilities.

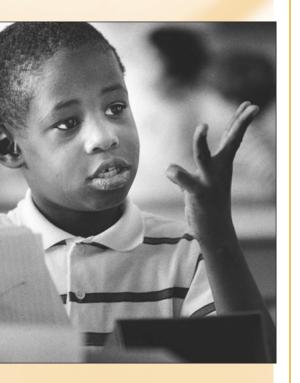
Community awareness — Regional centers continue to be "best kept secrets."

While we are truly a focal point for people with developmental disabilities and their families, we are virtually unknown outside of the population we serve. If we are to be the means to greater acceptance and inclusion of individuals with developmental disabilities in the community, we must find effective ways to educate the community about what we do and the people we serve.

Competition for finite resources – As has been demonstrated in the last decade, competition for resources exists even in times of plenty. Regional centers compete against services for other populations, such as the elderly and the mentally ill, and we compete against needs of a more visible type, such as the need to rebuild California's infrastructure. At the same time, expectations for regional center services continue to increase as consumers become more sophisticated and more empowered. The entitlement to services is fundamental, but we must balance it by careful stewardship, ensuring that dollars spent purchase services that are cost-effective and achieve outcomes desired by consumers and their families.

Innovation and change – The regional center system has matured and evolved to reflect changes in what society believes is right and just for people with disabilities. Our independence and strong community base have given us the ability to be innovative and adapt our model of service delivery to ensure that it remains relevant to the changing needs of the people we serve. We must endeavor to remain sensitive to what our community tells us it needs. At the same time, we must be ready to exploit changes in social policy and societal values, as well as advances in technology and information that will allow us to advance our mission.





Diversity – California is a microcosm of our increasingly ethnically diverse nation, and regional centers are a perfect reflection of this diversity. As true community-based organizations, we have always been able to understand and respond effectively to the differences across consumer and family groups we serve. While remaining responsive to all groups, however, we must keep sight of what unites us: recognition that people are our greatest asset and partnerships are the most effective way to achieve our common purpose.

Self-determination – We need to redouble our commitment to recognize the personal power of all people with developmental disabilities by promoting independence and encouraging initiative. We need to ensure that they have the knowledge, skills, and resources to make more of their own choices and exercise their right to make informed decisions in all areas of their lives.

Unifying the service delivery system – Thirty-five years ago California stopped building institutions and initiated the regional center alternative for carrying out the state's responsibilities for people with developmental disabilities. This community-based system has demonstrated that any individual with a developmental disability, regardless of the nature or extent of disability can, with proper support, live in the community. Repeatedly, judicial decisions, legislative initiatives, and executive orders have reaffirmed the right of all people to live, work, and otherwise participate fully in community life. In the next decade, California must unify its developmental services system. We must find appropriate community alternatives for the 3,800 people currently living in developmental centers and find strategies for redirecting into the community resources currently going to those institutions. The promise of this transition is that it will – at long last – result in adequate funding for the chronically under-funded

Informed, experienced leadership – The ultimate challenge for the regional center is to develop leaders who have the vision and commitment necessary to take us into that unknown called the future. This leadership must rise from within the community and build on the foundation set by the courage and persistence of those who have gone before. We must develop a leadership committed to quality and continuous improvement in all we do, accountability to one another, careful stewardship of our resources, and greater self-suffi-

ciency. We need a leadership motivated by possibilities and united in the vision of service to people with developmental disabilities and their families.

community services system.

um, we are reminded that with these challenges come significant opportunities. These include an apparent major commitment within the federal government to advance the cause of people with disabilities, as well as a commitment within the state to achieve a long-overdue unification of the developmental services system. Now more than ever, it is time for us and our communities to take up these challenges and be a part of shaping the future.

As we enter the new millenni-



